

Written Testimony of  
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Epilepsy Foundation of Connecticut  
March 16, 2012  
Public Health Committee

**Raised Bill No. 369 – An Act Concerning Authorization For The Use of  
Feeding Tubes and Antiepileptic Medications In School Settings**

Good Morning Senator Gerratana, Representative Ritter, Senator Welch, Representative Perillo and members of the Public Health Committee.

My name is Linda Wallace and I am Executive Director of the Epilepsy Foundation of Connecticut. I am also the mother of a young adult who has had epilepsy for 25 years. I am here today to express the Foundation's strong support of Raised Bill No. 369. This bill will allow the use of life-saving emergency medication, including diazepam rectal gel (marketed as Diastat AcuDial) to be administered to students by trained non-medical personnel, and, in turn, ensure that children with epilepsy are not needlessly denied access to the full range of educational experiences.

There are an estimated 3,000 children with epilepsy currently enrolled in Connecticut school districts. So, it is very important for you to understand the realities and risks for these children. Their seizures are unpredictable. And if their seizures are prolonged or clustered, it is a serious medical emergency and delays in treatment can cause irreparable brain damage and even result in death. Unfortunately, simply calling 911 is not an appropriate response as there is no guarantee that an ambulance will arrive within the critical first five minutes of the onset of the seizure.

Over the past two years, the Foundation has received numerous complaints from parents, teachers, school nurses and medical providers regarding children being denied Diastat in the school setting due to misperceptions regarding safety, misunderstandings related to state and federal law and misinterpretation regarding the ability of unlicensed personnel to administer it. In fact, Diastat is FDA approved and was designed to be administered by people without medical training, such as parents, teachers and other caregivers. It is a safe and effective treatment, even when administered by individuals without medical knowledge.

And finally, current State Department of Education regulations allow a qualified or trained school principal, teacher or licensed occupational or physical therapist to administer oral, topical or inhalant medicine and epipen injections to students with medically diagnosed allergies that may require prompt treatment to protect against serious injury or death. Coaches and athletic trainers may also give inhalant medication and epipens. There is no reason why children with epilepsy should not be protected as well.

To summarize, federal and state laws guarantee every child/student the right to participate in free, appropriate public education in the least restrictive setting. Schools are also required to provide many health –related services, including administering medicine, if needed, to students with disabilities, as either a reasonable accommodation or related service. The purpose of these laws is to ensure that children with chronic health conditions like epilepsy can be educated in the least restrictive environment and participate in extracurricular and recreational activities with their peers. The Epilepsy Foundation wholly supports these principles as being in the best interest of the child. We welcome the opportunity to work with the Department of Education and school districts across the state to provide training and develop procedures that will allow non-medical school personnel to administer Diastat and other anti-epileptic medication to children with epilepsy.

Thank you for introducing this legislation, providing us this time to testify and your thoughtful consideration of this critical legislation.